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ABSTRACT

This paper describes the inclusion of a 21-year-old woman, Joanna, with profound disabilities in a college class on educational methods of working with students with profound needs. This article presents the perspectives of the professor of the class, of Joanna's mother, and of a graduate student in the class. The professor reports on the positive effects Joanna's presence had on the class, including relaxing the class and developing student observational and programming abilities. Joanna's mother describes the family's long struggle to provide inclusive experiences for Joanna, the appropriateness of a 21-year-old attending a university program with peers, and the positive effects of this inclusion on Joanna. The fellow student explains how the inclusion of Joanna allowed students to address the real challenges of their profession and to "practice what they preached." (DB)

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INCLUSION IN HIGHER EDUCATION: PARENT, PROFESSIONAL & PEER IMPRESSIONS

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Introduction:

Joanna's attending classes at the University of Colorado at Denver seemed to have a profound effect of those involved in this endeavor. "Profound" is also Joanna's label. This article presents the personal perspective of Joanna's mother, Carrie Fronczyk, the impressions of one of her peers, Patsy Wagner, who is a veteran special educator and graduate student, and Joanna's professor, Dr. Deb Schell-Frank.

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Debra Schell-Frank

From Joanna's Professor:

TO THE EDUCATIONAL RESOURCES
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Inclusive education for all students is no longer whispered among radically thinking advocates but has become a battle cry. Long-range forecasts suggest segregation will be entirely replaced by progressive inclusion (Reynolds, 1991).

What does this have to do with Joanna, a 21-year-old, who has finished the public school program and is in need of ways to fill 24 hours of a mostly empty day? Joanna found herself caught in the dilemma described by Bates:

"For individuals with profound handicaps, exclusion is the all-too-common postschool experience. Exclusion typically means that young adults remain in their homes after their public school eligibility is exhausted and are forced into life-styles of isolation, dependence, and minimal community participation." (Bates, 1989, p. 266).

Joanna was introduced to me through her previous integration facilitator, Ann Milatchi. Ann and Joanna's parents had come up with a bold idea as part of Joanna's Futures Planning. They were suggesting that Joanna might benefit from attending a weekly class on the Denver campus of the University of Colorado. As coordinator for the Teacher III: Profound Needs program, they wondered if I would consider including Joanna in one of the classes I taught.

I recognized their petition as a novel idea worth exploring. I was teaching a methods class on working with students with profound needs. Because Joanna's needs are considered to be in the profound range, her attending class appealed to me as an opportunity to benefit her, my other

students and challenge my teaching ability. I could not have foreseen what a unique and timely opportunity it indeed turned out to be.

After an impromptu team meeting with class members, Joanna, her parents and her facilitator, Joanna arrived the following Tuesday evening. One of the students had volunteered to carpool with Joanna to ease the transportation burden for Joanna's parents. We set about trying to include Joanna without compromising the amount or intensity of information required for a graduate level methods course.

Joanna began at once to demonstrate her strengths as they had been recently outlined at her Futures Planning. She was a good group member; sitting quietly, turning her head toward a speaker and becoming more attentive when her name was mentioned; a good eater, nibbling on snacks the other students had brought, clapping her hands when I pushed her wheelchair past the cafeteria and explained it as the place where students go to buy food; affectionate, reaching toward the person sitting next to her, touching our hands, and in turn responding to touch.

We all felt an immediate need to determine ways to communicate with Joanna. Did she clap her hands and smile in connection with something said? When she cried out or her movements became more animated did it mean she wanted to leave? How could we find out what she was trying to tell us? Students volunteered to keep data on her repertoire of behaviors. Each week a different student would name, tally and write a running narrative on Joanna's behaviors. Another student would write a note home to accompany handouts and describe Joanna's evening.

One of the course assignments was to develop ideas for appropriate activities that met Joanna's needs. The students brainstormed potential activities for a 21-year-old in the home, community, leisure and self-care domains (Joanna's family felt a vocation was not a goal for Joanna at this time in her life). From this, each student chose a particular activity that appeared to be appropriate for Joanna and her family and expanded this by interviewing, researching and developing information packets for Joanna. Some of the projects included a resource booklet on massage therapy and convenient masseuses who had been interviewed and were willing to take Joanna on as a client. This idea stemmed from the student noticing how Joanna appeared to enjoy

having her shoulders massaged during class breaks. Another student made arrangements for Joanna to be a member of another teacher preparation class the following semester.

While including Joanna had not been offered as an option, students did not complain about the struggle to attend to Joanna while paying attention to course lectures, presentations and guest speakers. The atmosphere of the classroom tended to relax. One of Joanna's peers would determine she needed a break from the lecture and would wheel her out into the foyer. Food became a common way to engage Joanna and relax the rest of us. Although it was unspoken, the idea of missing a few minutes of classroom activity was no longer threatening. After all, public school classrooms don't function with full attention, and limited distractions. It began to occur to me that teacher training courses could more exactly model the atmosphere of the public school classroom and in turn benefit the teacher in training if we practiced what we preached and celebrated diversity in our graduate courses.

As a culminating activity on the last evening of class, we met with Joanna's family, her former integration facilitator and several other interested families. The students presented their final projects and rationale for choosing that particular activity. We exchanged ideas with peers, families and friends on continuing our efforts to include students with special needs in higher education. While this is a relatively new concept (Marsha Forest called it "cutting edge stuff"), it certainly is timely and relatively easy to implement. This is not to say there have not been obstacles. We continue to struggle with keeping Joanna engaged without missing too much of the scheduled agenda. There is also the issue of expanding Joanna's environment on campus. How can we involve her in campus-wide activities? How can we enlarge her circle of friends?

Joanna is finishing up her second semester with the Profound Needs teacher training program at the University of Colorado at Denver. We haven't written formal programs, determined specific goals and objectives or scheduled Joanna's time. That may come later if we determine it will benefit Joanna and/or her classmates. For now we're comfortable with recognizing her as a peer and a friend.

As a professor of special education, I have to admit that Joanna has simplified my role in countless ways. Learning "happens" without my direction; awareness is heightened to a tangible level as students seek ways to include Joanna on an on-going basis. I thank her, her family and the members of her class for allowing me this golden opportunity.

Reynolds, M.C. (1991). Journal of the National Center for Outcome Based Education, 1, 11-14.

Bates, P. (1989). Vocational training for persons with profound disabilities in F. Brown and D. Lehr (eds.) Persons with profound disabilities: Issues and practices, Baltimore: Brookes.

From Joanna's Mother:

For most of Joanna's life we have been struggling as parents to provide her with opportunities to develop friendships. As a toddler, when she began to demonstrate her differences, friendships and inclusion were very limited. I can recall only one time when Joanna was asked by a friend and his mother to accompany them on an outing. The few birthday parties that she attended were friends of the family and she never experienced a "sleep-over" with a friend.

When we saw the pattern that was developing in Joanna's life we attempted to build into her Individual Educational Plan opportunities for socializing with her typical peers and developing friendships. We felt the best way to achieve this was by integrating her into regular education classes. Attempts were made but were usually unsuccessful. I feel that this was due in part to the fact that Joanna was not home schooled until the age of 17. Mary Falvey stated in a recent integration conference that children need three things to develop and maintain friendships:

- (1) Close proximity
- (2) Shared experiences
- (3) Equal opportunities

These three things did not exist for Joanna.

Even after Joanna was home schooled, the concept of Inclusion was new and frightening to many professionals. To us as parents Inclusion was the answer to Joanna's many years of

isolation and exclusion. We saw it as the key that would open the door to new and exciting opportunities for our daughter. But once again due to various circumstances we were unsuccessful. It was difficult developing friendships with peers who had been nurturing friendships with their classmates for years.

When Joanna completed high school we realized that nothing was in place for her. Like so many young adults with disabilities she was now doomed to spend 24 hours a day at home with her parents. That was when we decided, with the help of Ann Malatchi, a friend and integration specialist, to develop a Futures Plan for Joanna. One idea that came out of the planning was to provide Joanna with the opportunity to attend a college level program on a university campus. This seemed to be the normal progression for someone completing high school.

We felt that attending a university program would afford Joanna the opportunity to develop new friendships, to be exposed to large numbers of people with common goals, to participate in activities in a new setting, to be challenged in new learning situations, and to be able to demonstrate her capabilities. It also gave others the opportunity to experience the gifts and talents that Joanna had to offer.

After approaching the necessary people at the University of Colorado at Denver, Joanna was welcomed into the program with ease. For once we didn't have to validate Joanna's right to be included. At last we were heard and our dream for our daughter became a realization. The course instructor and her classmates demonstrated the ease of inclusion and the benefits to both Joanna and her classmates.

Seeing Joanna with her classmates proved what we knew to be true all along. Her body language showed us that she was aware of her surroundings because she was accompanied by peers who considered her their friend, classmate and equal. Her posture improved, her attention became more focused and her level of alertness was heightened.

We will be eternally grateful to a professor and class members for their willingness to include Joanna, and for their realization that diversity and differences are beneficial and that everyone can learn and contribute when given the opportunity.

From Joanna's Peer:

As students graduate from high school, they anxiously plan their whole new life. Some join the work force, while others join the military. Some look forward to entering college. Joanna is one, from the class of '91, who had the dream of going to college. This dream, however, was not the easiest to turn into reality. Joanna has a rare, degenerative, enzyme deficiency which has forced her to be dependent on others for almost all of life's basic needs.

Joanna and her family knew the University of Colorado at Denver had a graduate program designed to prepare students to work with people who have profound needs. They felt the students in this program would have an understanding of Joanna's desire and need to attend college classes. I was a student in the class that Joanna wanted to attend. This was how my friendship with Joanna began.

I believe all people have the right to be included in any environment they choose. Therefore, I was excited about the possibility of Joanna having the opportunity to attend college. I live in the same part of the city as Joanna, so I volunteered to carpool with her to campus. Outside of the fact that she did not share my same taste in music, it was nice to ride with someone to class.

The next challenge was to involve Joanna in a way which was meaningful to her. The group decided it was important for Joanna to get to know her fellow classmates. At the beginning of each class session, classmates reintroduced themselves. Each week a different person sat next to Joanna in an effort to get acquainted. At break, Joanna went for a walk or "hung-out" with different classmates.

Although Joanna did not always share the same love for the topic discussed as the rest of us, it was clear she enjoyed being with us. She was always attentive whenever her name was mentioned and seemed to be more alert to the voices of students that she was familiar with and to the voice of the instructor. She appeared very attentive when the only male student in the class was talking. She was more lively whenever there was more interaction. It was quite clear she

was not happy with the lecture format. It was also clear she was not particularly fond of one classmate. When this person spoke, Joanna would often become agitated and restless.

Joanna provided us, her fellow classmates, with an experience we will never forget. Our goal in graduate school was to learn how to become integration facilitators for people with profound needs. Joanna gave us the opportunity to "practice what we preached". I certainly enjoyed getting to know Joanna and the many gifts she has to offer. Mary Falvey, in a talk she gave in Denver in April of 1990, said "developing friendships is an art, not a science". Joanna helped to reinforce this for me. As I work as an advocate, a friend, and a teacher of people with profound needs, I will never forget my relationship with Joanna and all that she taught me.

Thanks, Joanna!